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## Understanding immunopathology of severe dengue: lessons learnt from sepsis

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*Published in:*  
Current opinion in virology

*DOI:*  
[10.1016/j.coviro.2020.07.010](https://doi.org/10.1016/j.coviro.2020.07.010)

**IMPORTANT NOTE:** You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

*Document Version*  
Publisher's PDF, also known as Version of record

*Publication date:*  
2020

[Link to publication in University of Groningen/UMCG research database](#)

*Citation for published version (APA):*

Aguilar Briseño, A., Moser, J., & Rodenhuis-Zybert, I. (2020). Understanding immunopathology of severe dengue: lessons learnt from sepsis. *Current opinion in virology*, 43, 41-49.  
<https://doi.org/10.1016/j.coviro.2020.07.010>

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# Barriers and facilitators to accessing insulin pump therapy by adults with type 1 diabetes mellitus: a qualitative study

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Received: 22 July 2020 / Accepted: 9 August 2020  
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## Abstract

**Aims** Uptake of continuous subcutaneous insulin infusion (CSII) by people with diabetes (PwD) in Ireland is low and exhibits regional variation. This study explores barriers and facilitators to accessing CSII by adults with Type 1 diabetes mellitus.

**Research design and methods** A qualitative study employing focus groups with adults with Type 1 diabetes mellitus ( $n = 26$ ) and semi-structured interviews with health care professionals (HCP) and other key stakeholders ( $n = 21$ ) was conducted. Reflexive thematic analysis was used to analyze data, using NVivo.

**Results** Four main themes comprising barriers to or facilitators of CSII uptake were identified. These included: (1) awareness of CSII and its benefits, (2) the structure of diabetes services, (3) the capacity of the diabetes service to deliver the CSII service, and (4) the impact of individuals' attitudes and personal characteristics—both PwD, and HCP. Each of these themes was associated with a number of categories, of which 18 were identified and explored. If the structure of the health-service is insufficient and capacity is poor (e.g., under-resourced clinics), CSII uptake appears to be impacted by individuals': interest, attitude, willingness and motivation, which may intensify the regional inequality in accessing CSII.

**Conclusions** This study identified factors that contribute to gaps in the delivery of diabetes care that policy-makers may use to improve access to CSII for adult PwD.

**Keywords** Type 1 diabetes · Insulin pumps · Continuous subcutaneous insulin infusion · Medical device · Diabetes technology · Health-services research · Qualitative research

This article belongs to the topical collection Health Education and Psycho-Social Aspects. Managed by Massimo Porta and Marina Trento.

**Electronic supplementary material** The online version of this article (<https://doi.org/10.1007/s00592-020-01595-5>) contains supplementary material, which is available to authorized users.

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## Introduction

Continuous subcutaneous insulin infusion (CSII) is widely used in particular in the pediatric population of people with diabetes (PwD) [1] due to its better accuracy in insulin dosing and flexibility in insulin adjustments [1]. While scientific evidence supports the use of CSII [2–4], it requires more education from the medical team, more intensive follow-up and initially more effort from the PwD to gain the optimal benefit from the treatment. Some evidence suggests that careful selection of potential CSII users is required to ensure that the appropriate PwD is offered CSII [5]. A further factor to consider is that CSII is more expensive [6]. The therapy is reimbursed in many countries [7], nevertheless, uptake of CSII therapy varies internationally and regionally, and seems not to be determined only by reimbursement strategies [7–10]. Uptake also varies in different age-groups and is highest in younger populations [11, 12] probably largely because CSII is recommended as a “first choice treatment” for preschool children by the International Society

for Pediatric and Adolescent Diabetes [13, 14]. In Ireland, for example, uptake is 5-times higher in children, than in adults (34.7% vs. 6.8%) [10], but still, significantly lower than in the USA, where uptake is similar in adults and children (60%), although, as only 76 clinics were involved in the T1D Exchange register across the USA, it may not represent the national picture [15]. In the Euro Diabetes Index 2014, a report comparing the quality of diabetes care across Europe, access to CSII in Ireland was assessed as average (between 5 and 15% of all type 1 diabetes population) compared to Austria, Finland, France, Germany, Luxembourg, Netherlands, Norway, Sweden and Switzerland with uptake of CSII over 15% [14]. The recently published study on uptake of CSII in Ireland suggests that the rate has not changed since then and continues to be below 15% in the population (10.5%) [10].

The reasons behind disparity in the international and national distribution of CSII are not well explored. Results from a national survey of adult diabetes clinics suggest that under-resourcing of diabetes services is a major contributor to the low uptake in Ireland [16], but the determinants of access to diabetes-related technology require further investigation. Some barriers to uptake may be related to preferences of PwD [17, 18], or reimbursement strategies [7], as well as lack of specific guidelines and policy documents [19]. In Ireland, there are no clinical guidelines or recommendations regarding CSII use in adults and the criteria for eligibility to commence CSII are neither standardized, nor well described as, for example, in the UK NICE guidelines [20]. Although full reimbursement is provided, access to CSII varies regionally, suggesting that this issue is complex and requires further investigation. The lack of a diabetes registry and clinical audits in Ireland do not allow for comparison between diabetes-related outcomes (for example, hemoglobin HbA1c) in areas with better or worse access to CSII. Based on an international comparison from 2014, control of type 1 diabetes mellitus (T1DM) reported by one clinic in Ireland demonstrated room for improvement and it is to be expected that this picture would be similar at other sites [21]. CSII may have the potential to improve the quality of care for type 1 diabetes in Ireland. However, as the uptake of CSII remains low in Ireland when compared to international evidence, in particular in adults with type 1 diabetes, the problem of access to CSII remains, and the aim of this study is to explore the barriers and facilitators to accessing CSII by PwD in Ireland.

## Materials and methods

### Qualitative design

This study used a qualitative approach to capture a broad range of determinants of uptake of CSII [22]. To gain insight

from a variety of experiences and opinions, face-to-face semi-structured interviews with health care professionals (HCP) and other key stakeholders, patient advocates and adult PwD across Ireland were conducted. Additionally, focus groups with adult PwD in four Irish cities from different geographical areas were performed. Individual interviews and focus groups were combined to enhance data completeness [23], as well as for pragmatic reasons related to the recruitment strategy.

### Sampling and recruitment

This study employed purposive sampling, a technique widely used in qualitative research to identify and select individuals (or groups) that are especially knowledgeable about a phenomenon of interest [24]. For individual semi-structured interviews, recruitment was guided by respondents' professional role (to gain different perspectives), and the level of uptake of CSII and experience in CSII (to explore different barriers and facilitators in areas of low and high uptake of CSII). Some participants (endocrinologists, nurses, dietitians working in diabetes clinics) were recruited during data collection for a national survey of the availability of CSII in Ireland [16], and some (policy-makers, patient advocates, insulin pump company representatives, and those from rural areas) through the snowball technique. This method is often used to find and recruit "hidden populations" or groups not easily accessible to researchers through other sampling strategies. Potential "experts" may be included in the study at the suggestion of the interviewees who recommend potential key informants [24, 25].

Focus groups were conducted to explore the experiences of PwD from different demographic locations (from areas of low, average or high uptake of CSII [9, 10]), and of those with an experience of successful access to CSII, and those not on CSII. PwD were recruited through online social media groups (Facebook, Twitter) and through support of Diabetes Ireland (the national diabetes-focused charity), Thriveabetes (blog and annual conference for PwD) and through local T1DM support groups. Across each area, effort was made to recruit a diverse group of participants with respect to sex, diabetes duration, place of living (urban vs. rural), and technology use. Critical recruitment criteria were: having T1DM, and age over 18. Those who commenced CSII before age 18 or outside Ireland were excluded from recruitment. To ensure participation of PwD on treatments other than CSII, focus groups attendees were invited to discuss "accessing new technologies in diabetes care", not specifically CSII.

## Data collection

Interviews and focus groups were conducted between June and September 2018 by K.A.G. The same topics (Table 1) were discussed in every conversation. Topic guides were developed by all co-authors, based on the findings of a literature review (including conceptual frameworks of access to health care [26], technology utilization [27] and existing literature about CSII distribution worldwide), and the results of the studies on the uptake [9, 10] and availability [16] of CSII in Irish diabetes clinics. During each conversation, a map of uptake of CSII in Ireland was presented to participants and discussed (Appendix S1). Topic guides were pretested with one PwD and one HCP.

## Data analysis

All focus groups and interviews were recorded, transcribed (by K.A.G. or external professional transcribers) and error-checked for accuracy and consistency. Transcripts were de-identified (pseudonymized, with access to originals granted

to K.A.G. only) and analyzed thematically, according to the principles of reflexive thematic analysis [28]. All analysis was performed by K.A.G., in consultation with co-authors. An inductive approach to analysis was used—the analysis was data-driven, and conducted according to Braun and Clarke’s 6-phases of thematic analysis [22]. After data familiarization, three rounds of coding (manual open coding, and two rounds of open coding with use of qualitative software—NVivo, ver. 12) were conducted. Codes were merged into categories and sub-themes and then, based on the categories, broader overarching themes were generated and checked against each other and back to the original dataset. Developed themes were named, defined and reported [22]. More information about the methodological approach is provided in Appendix S2. In this report, anonymized quotations representing themes and categories are presented, followed by an abbreviation of participant group and, if available, the area of uptake where the participant works/lives.

The study was approved by the research ethics committee of the Royal College of Surgeons in Ireland (RCSI, REC ref. 1494b) and informed consent was obtained from

**Table 1** Key areas explored and discussed in Interviews with health care professionals and key stakeholders and Focus groups with people with diabetes on accessing insulin pump therapy

No.	Topic of discussion <sup>a</sup>	Respondents
1	Experience With type 1 diabetes mellitus (T1DM) With continuous subcutaneous insulin infusion (CSII) therapy PwD: their diabetes story/background	HCP <sup>b</sup> , OKS <sup>b</sup> , PwD <sup>b</sup> HCP, OKS, PwD PwD
2	Access to CSII Exposure to CSII  Decision to commence CSII (How? Who?) PwD’s journey to access CSII Criteria “Good” pump clinic	HCP, PwD—those not on CSII asked first HCP, PwD HCP, OKS, PwD HCP, PwD HCP, OKS, PwD
3	Results of previous studies (Barriers) Availability of CSII in Irish diabetes clinics (1/3 not providing any CSII services, only 45% providing training to commence CSII) Low uptake of CSII (6.8% of adults, 34.7% of children with T1DM on CSII)	HCP, OKS, PwD HCP, OKS, PwD
4	Determinants of uptake Map of uptake—geographical differences “My area” vs. other areas	HCP, OKS, PwD HCP, PwD
5	What can be done to improve the uptake? International comparisons What policy-makers could do?	HCP, OKS HCP, OKS, PwD
6	Importance of the access to diabetes-related technology (CSII, CGM, FGM etc.)	HCP, OKS, PwD
7	Summary of what has been discussed + additional comments from participants	HCP, OKS, PwD

<sup>a</sup>While the same general areas, outlined above, were covered with all participants, tailored questions were also asked in particular groups of participants, and probes used to encourage and enable a fuller elicitation of responses to particular questions

<sup>b</sup>HCP health care professionals, OKS other key stakeholders, PwD people with diabetes

all participants. Details of the interview/focus group were provided in advance and consent was obtained prior to data collection. To minimize bias, Standards for Reporting Qualitative Research (SRQR) [29] were used to guide the data collection and reporting (Appendix S3).

## Results

Twenty-one interviews and four focus groups were conducted. The participants ( $n=47$ ) included 28 PwD and 19 HCPs or other key stakeholders (OKS) (Table 2). Interviews lasted a median of 62 (range: 45–95) minutes, and focus groups lasted for a median of 121.5 (range: 113–141) minutes. Discussed topics aligned with four main themes, including 18 categories that could be either barriers or facilitators, which were developed and integrated into a “Conceptual Framework of accessing diabetes-related technology” (Fig. 1). The four themes were (from the least frequently discussed to the most): awareness, structure, capacity and impact of an individual. The brief overview of the categories within the themes and the frequency of discussed aspects are presented in Tables 3 and 4, respectively. The heterogeneity in uptake and unequal access to CSII were described as an independent, cross-cutting theme “inequality” that was present in all main themes and described the research problem. Quotes representing themes are provided in Appendix S4 in a numerical order. As the topic was complex, all themes were interrelated, and some categories may fit into two different themes. The description of the themes and categories is based on the qualitative analysis only. The most frequently discussed categories within the themes (highlighted in Table 4) are described in more detail. Additional analysis of comparisons between HCP’s and PwD, as well PwD on CSII and not on CSII are provided in more detail in Appendix S5.

### Research problem: inequality

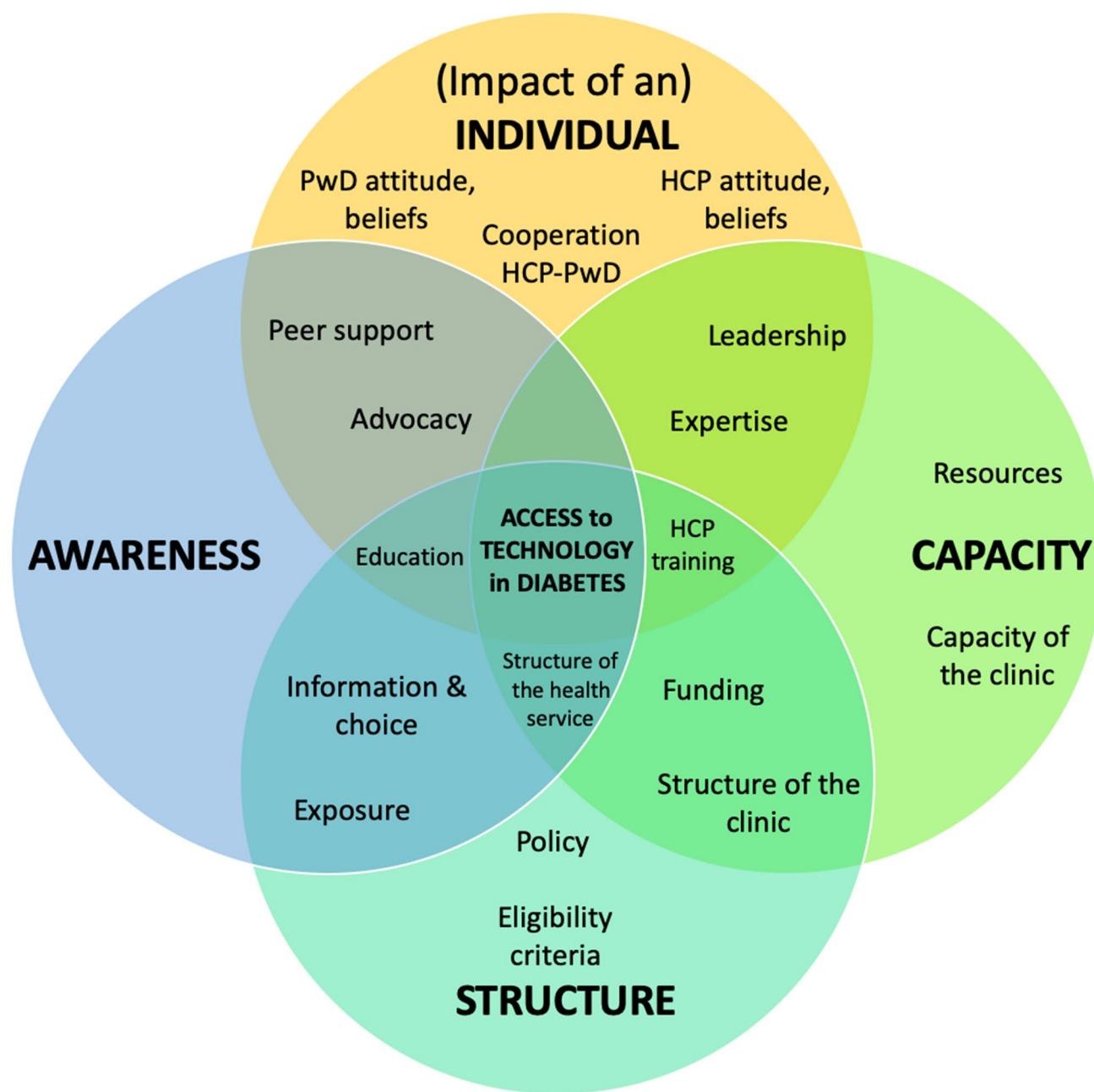
All four themes are influenced by the cross-cutting sub-theme inequality, and the discussion about inequality in accessing CSII was mainly related to a place where PwD lives. There was general agreement among participants that the uptake of CSII is low in Ireland, and that the “postcode lottery”, understood as an unequal provision of services, exists. *This postcode lottery issues. If you live in the right place you get the best care, if you live in the wrong place you get screwed* (HCP1, high uptake). This disparity was “frustrating” for all participants and it was “obvious” that low uptake is caused by the lack of local access to CSII: participants from these areas have to travel to access care, have time to travel and perhaps have to pay for it; thus, it requires significant motivation and willingness. In addition, the need to travel may limit consultation duration and access

**Table 2** Characteristics of participants of the qualitative study, both focus groups and interviews on the barriers and facilitators to accessing insulin pump therapy

All Participants	<i>n</i> (%)
Gender	
Male	20 (43%)
Female	27 (57%)
Area of CSII uptake <sup>a</sup>	
Low	12 (28%)
Medium	8 (18%)
High	24 (54%)
Not applicable	3
Type of care <sup>a</sup>	
Public only	29 (66%)
Private only	11 (25%)
Public and private	4 (9%)
Not applicable	3
<i>People with type 1 diabetes</i>	
Age group	
18–35	10 (36%)
36–55	12 (43%)
56 and over	6 (21%)
Diabetes duration	
0–10 years	5 (18%)
11–20 years	8 (29%)
21–30 years	8 (29%)
30 years and over	7 (25%)
On CSII:	
For up to 2 years	6 (21%)
3–5 years	6 (21%)
6 and more (up to 15)	8 (32%)
Not on CSII	8 (25%)
Traveling to a different county to access care:	
Yes	8 (29%)
No	20 (71%)
Technology use	
Yes—insulin pump and CGM/Libre	17 (61%)
Yes—insulin pump only	3 (11%)
Yes—CGM/Libre only	5 (19%)
No	3 (11%)
<i>Other key stakeholders</i>	
Type of profession:	
DNS/ANP	9 (43%)
Endocrinologist/diabetologist	6 (29%)
Dietitians, Company reps, Patient advocates	6 (29%)
Involved in policy-making	
Yes	5 (24%)
No	16 (76%)

<sup>a</sup>“Not applicable” cases are not included in the calculations of the percentages





**Fig. 1** Conceptual framework of accessing diabetes-related technology. The main themes and categories that are either barriers or facilitators to uptake and availability of insulin pump therapy

to education compared to PwD who live close to well-established clinics. Their choice of diabetes team or consultant is limited, and they have to “fight” much more than PwD living in areas where access to CSII, and what they perceive as “quality of care”, is more available. *You know what it is reflecting? The diabetes teams. Your concentration of insulin pump therapy is reflecting the dedication of the diabetes teams, or the experience of the diabetes teams, without a shadow of a doubt.* (OKS 1). (Appendix S4, Q1–Q2). In the

following, the four main themes, determining this inequality, are discussed.

### Awareness

Awareness is related to a knowledge, or perception about existing diabetes-related technology, available choices, options and need for improvement. If people are aware of options, if they know that the options exist and how it can

**Table 3** Themes and categories within the themes: definition

<i>Awareness</i>	
Exposure	Exposure relates to familiarization with CSII thanks to HCP/MDT (offering/explaining CSII), a person on CSII, advert, online discussions (DOC) or events for PwD; HCP may be exposed (or not) during their professional training, or involvement/experience in the pediatric diabetes clinics. The exposure can be generated thanks to a structure
Education	Diabetes education is essential to learn the self-management, carb-counting, it is also an opportunity to expose PwD/HCP to CSII; good quality, standardized education is a core of diabetes treatment and self-management and essential to provide skills and awareness of existing options; it is a key requirement to commence CSII
Information & choice	Information about CSII, its benefits, as well as pathways and possibilities to commence it; the choice of treatment (as well as a device), is a facilitator, however, the choice of CSII in Ireland is limited; this category is also a part of the theme structure
Advocacy	Formal “fight” for access, highlighting the gaps and issues, contacting politicians, writing letters to hospital managers, organizing support groups, formal complains about the gaps in services provision etc.; this category was mainly discussed in a context of what adult PwD could learn from parents of children with diabetes, who are more effective in their “fight”
Peer support	Through peer support—online or face to face—PwD are getting exposed to CSII, can reach the information that was unavailable to them in their diabetes clinics, can learn about therapies, options, places to go if interested in accessing technology
<i>STRUCTURE</i>	
Structure & clarity (of the health service)	The structure that is related to the clarity, standards of care, continuity of care, established referral pathways, access to the private offer and overall transparency, pathways and regulations within the health-service
Eligibility criteria	Criteria to commence CSII that are not-standardized, contradictory, and non-transparent in Ireland, and depend on a HCP preference and training; meeting the medical criteria (i.e., hypo-unawareness) is an important facilitator of access, and some PwD “do what they must” to only meet the criteria (even deteriorate their diabetes management), thus the medical criteria mandate may limit the access
Policy	This category was discussed mainly in the context for the need of policy-makers’ involvement and drive to improve access to CSII, but also in the context of potential solutions to improve it, reasons why “diabetes” is not a priority, and use of research and data to inform the policy-makers
Structure & clarity (of the clinic)	Structure of the clinic includes dedicated CSII days, staff members, information leaflets, dedicated team, clarity related to the information and the waiting lists (“smokescreen”); this category was also discussed within a context of the continuity of care, as if it’s lacking, it was perceived as a barrier; this topic is directly associated with clinic’s capacity
<i>CAPACITY</i>	
Resources	This category was mentioned as one of the main barriers and facilitators of access. Resources relate mainly to the number of health care professionals, multidisciplinary team including nurses, dietitians, endocrinologists, and team work and agreement within the team
Capacity of the clinic	The capacity related mainly to physical space, facilities in the clinic (i.e., software, computers), perceived workload, the support from the hospital management, and cooperation with the insulin pump company reps. The involvement of company reps was a facilitator, as they usually provide the technical training to commence CSII
Funding	Funding was mainly discussed in a context of health care-related costs (i.e., posts for health care professionals) rather than reimbursement. The lack of funding for MDT members was perceived as one of the main barriers within this theme. As part of this category tender, and local budget (Local Health Offices) were discussed
Expertise	This category was discussed at the individual level (individual HCP’ expertise in CSII therapy), as well as the diabetes team (MDT) expertise. The lack of expertise was the obvious barrier to accessing/offering CSII, competence and confidence (parts of the expertise) were perceived as facilitators.
HCP training	HCP’s training in CSII was perceived as a facilitator—trained HCPs, if workload permits, were more likely to offer CSII to PwD. If HCP’s are not trained it is unlikely that they will offer it to PwD. This category included the specialist (endocrinology) training, the advantages and disadvantages of the Irish system, the lack of standardized exposure to CSII while in medical training, and the fact that other HCPs (GPs etc.) are not aware of CSII, was discussed as a barrier

**Table 3** (continued)*INDIVIDUALS*

HCP—attitude, interests, beliefs, etc.	The impact of individual health care professional was the mostly discussed category either as a barrier or facilitator of CSII access and uptake. This included attitudes (toward CSII, diabetes technology, openness) as well as interest in diabetes (mainly T1DM), and beliefs, such as "CSII is for children only", or very time-consuming or complicated vs. "just another way of insulin delivery". The older age of a HCP was perceived as a barrier to CSII uptake
PwD—attitude, interests, beliefs, etc.	PwD's positive attitude toward technology in diabetes, empowerment and just a willingness to commence CSII were the driver of CSII uptake. Those empowered, motivated, interested, and really wanting CSII were much more likely to get it, than those not willing to "fight" as for CSII. Of other aspects, personal characteristics, and psychological aspects (diabetes distress, burnout, and good well-being
Cooperation HCP—PwD	This category was mainly highlighted by PwD, as if a HCP does not want to listen to a PwD or respect the PwD decision, a PwD may just change the clinic and a HCP. Good and respectful cooperation was perceived as a facilitator, whereas the lack of it—as a barrier
Leadership	No leadership, no leadership skills, no interest in T1DM, willingness to "bother" with setting up a CSII-friendly clinic, as well as no push or encouragement of the PwD to commence CSII from the diabetes team was perceived as a barrier to access. "Diabetes champions", "experts", leaders who are vocal and capable of arranging CSII clinic and those who can influence the health-services provision, were assessed as facilitators

**Table 4** The frequency of discussed categories in particular themes, as a whole theme, and in a separate context of barriers and facilitators

All themes	All (%)	Barriers (%)	Facilitators (%)
(Impact of an) individual	29.64	29.27	29.31
Capacity	27.98	28.67	26.80
Structure	24.06	25.92	21.97
Awareness	18.32	16.15	21.92
<i>CATEGORIES WITHIN the THEMES</i>			
<i>AWARENESS</i>			
Exposure	37.71	36.33	44.74
Education	29.44	30.66	25.76
Information & choice	12.33	20.31	6.17
Advocacy	15.19	12.70	15.24
Peer support	5.33	0.00	8.10
<i>STRUCTURE</i>			
Structure & clarity (of the health service)	38.76	34.31	43.18
Eligibility criteria	25.20	21.90	28.47
Policy	23.80	28.35	19.30
Structure & clarity (of the clinic)	12.24	15.45	9.05
<i>CAPACITY</i>			
Resources	42.97	30.47	54.20
Capacity of the clinic	16.46	16.50	16.42
Funding	15.57	28.60	3.86
Expertise	15.05	12.10	17.71
HCP training	9.95	12.32	7.81
<i>INDIVIDUALS</i>			
HCP—attitude, interests, beliefs, etc.	45.53	42.46	48.00
PwD—attitude, interests, beliefs, etc.	34.71	34.59	35.00
Cooperation HCP—PwD	13.57	12.93	3.00
Leadership	6.19	10.02	14.00



affect their lives and diabetes care, they are more likely to ask about and consider them. Exposure and Education were the mostly discussed categories of Awareness, among others: Information & Choice, Advocacy and Peer Support (see Table 4).

### Exposure

Awareness about CSII can be raised in many ways—for example, through exposure through a HCP/diabetes team offering this choice. However, of those participants who commenced CSII, fewer than half of the PwD ( $n=9$  of 20) (and from the areas of high uptake only) had heard about CSII from their diabetes teams or had been offered it by their endocrinologist. Others were “fighting” to commence CSII, and were exposed through meeting other PwD on CSII, or the diabetes online community (DOC). For some participants, attendance at the focus group was the first time to meet other people on CSII, or that they heard of CSII. Exposure to other sources—other PwD using CSII, events for PwD, face-to-face support groups etc.—is therefore crucial, if diabetes teams do not offer technology. In this context, online resources through the DOC may be a source of information. Whether a PwD will conduct an online research, comes down to individual factors (theme described in-depth later), and access to a source of information, i.e., internet. The category of exposure relates to HCPs also—those from the areas of low uptake may not be familiar with CSII, never or not much exposed, thus not interested in developing the service or skills. This relates to participants’ impression of the “quality of care” that is usually associated with offering CSII. Beyond its existence, another aspect is the “awareness of CSII benefits”. Notably, some focus group participants “got encouraged to CSII” by other participants commenting on its benefits. Moreover, use of other technologies (e.g., Continuous or Flash Glucose Monitoring—CGM or FGM) was a facilitator mainly for PwD, both through exposure, getting used to having something “attached”; and engaging more in their care because of having more clinical information (Appendix S4, Q3–Q7).

### Education

Diabetes education, in particular access to structured programs, was an integral part of awareness of technology, and a facilitator to its uptake. PwD may learn about different treatment options, while attending structured education programs provided locally by their diabetes teams. Overall, education is crucial to raise “awareness” of options and choice, but access to education is an issue in Ireland. *That is why I want more education, I don’t think patients are aware that they are doing a bad job...* (HCP1, high uptake). In some cases, CSII training is the first time and one reason to

educate a PwD: *That’s to see the diabetic nurses for the carb counting, the dietitian and to get taught on how to use the pump and how to carb count. Because in 20 years I’ve never been taught any of that stuff ever* (PwD2, FG, low uptake). For some PwD, however, education itself is a key solution to improving their diabetes control and may consider CSII unnecessary for that reason. According to HCPs discussing the map of CSII uptake, areas where uptake is high, are usually areas where structured education (e.g., DAFNE—Dose Adjustment for Normal Eating), is available, and low in those, where there is no access to DAFNE (Appendix S4, Q8–Q10).

### Structure

Structure relates to arrangement and organization within the health service and individual clinics. According to participants, structure, if it existed, was an important determinant of access, and, in turn, lack of structure, clarity or transparency related to information and funding was highlighted as a barrier. *Why can’t we just have a clear outline? This is the structure for access to technology. This is the structure to access to the diabetes treatment. Here is how you do it this way, and here is why you can’t do it the other way* (PwD3, FG2, high uptake). Categories that this theme is based on include issues specific to the health-service or clinic, as well as criteria to commence CSII and policy-making. The minority of PwD, however, described their experience of accessing CSII as “easy and straightforward”, usually the process—due to the lack of structure also—was vague and not transparent (Appendix S4, Q11). See Tables 3 and 4 for more information.

#### Structure of the health-service

All participants agreed that the structure and a clear pathway to commence CSII were facilitators to CSII uptake. Elements of the structure of the Irish health service highlighted by participants as “facilitating” were related to structured referrals (if CSII was unavailable locally), agreed pathways, standardized criteria to commence CSII, and—if it existed—continuity of care. However, the latter category was mainly discussed by PwD and usually mentioned as a barrier. Specifically, seeing a different HCP at each appointment limits conversations around modifications of therapy and happened often in the public service. *Do you actually get to see your consultant? Like, in last 6 years, I’ve probably seen my consultant once. It was always somebody else* (PwD4, FG2, high uptake). Some hospitals have a structured agreement that PwD willing to commence CSII can commence it publicly elsewhere and continue their follow-up care in the local center, but this constitutes a challenge for the receiving hospitals and increases their workload. In some areas, public

referrals to commence CSII were not available at all. Therefore, for PwD from these areas (low uptake), commencing CSII in a private setting was the only one option. Those PwD praised private clinics for their structure: “value for money”, quick and clear processes, as well as amount of “time” that HCP spend with a PwD, and greater continuity. Notably, none of the participants living in the areas of the high uptake commenced CSII privately—only those from the areas of low and medium uptake, in keeping with unequal access to services (Appendix S4, Q12–16). On a clinic-level, structure includes availability of information sheets, having dedicated T1DM or CSII clinic, clear roles of the multidisciplinary team (MDT) members (e.g., a dedicated technology nurse). A well-structured pathway includes, i.e., group education for T1DM followed by encouragement to consider CSII. According to some HCPs and PwD, not all PwD are well-informed, and their attitudes toward CSII might be biased by negative beliefs. This, however, works both ways, as some PwD might be dissatisfied with CSII treatment when they are only made aware of the benefits. Accurate, reliable, practical information, and a discussion of the pros and cons of CSII should be offered as a “standardized education package” to every PwD so they can make an informed decision whether or not to commence the treatment.

### Eligibility criteria to commence CSII

The second most important theme and facilitator of CSII uptake related to structure were the “eligibility criteria”—when a PwD meets them. If not—it was discussed as a barrier. Decision of PwD’ eligibility or suitability to commence CSII is usually made by HCP, based on their beliefs, experience, and certain clinical criteria, which, in Ireland, are not unified. Lack of standardization intensifies the “postcode lottery”, as this decision then depends on individuals and diabetes teams, not the structure, and is perceived as a barrier. *I have met so many people who have said, “my diabetes is too bad for a pump.” Or I have met people who have said, “my diabetes is too good for a pump”. And you are like, how can you be too bad or too good?* (OKS 2). There was an impression, that for those who meet the medical criteria such as hypo-unawareness or insufficient diabetes control despite MDI, access is easier than for those who have a preference toward CSII, for lifestyle reasons. In some cases, PwD “have to lie to access CSII” or purposely allow their diabetes control to deteriorate to meet clinical criteria. *I think one of the criteria is that you have to have a lot of lows, so I worked very hard and craved very hard as well, and there were loads of lows involved in my day-to-days. So yes, I came up to it fairly fast and after that I think it was three or four months after I asked to get the pump* (PwD5, FG, medium uptake). According to some PwD, a “mandate” to attend structured diabetes education program prior to commencing CSII may

be perceived as a barrier, since availability of such programs is limited and the waiting lists in some areas of Ireland are long, what makes access to CSII more difficult. (Appendix S4, Q17–Q19).

### Capacity

Clinics’ capacity, understood as factors associated with (in) ability to provide CSII, was the second most frequently discussed theme in the entire dataset and is one of the most important determinants of uptake and availability of CSII. This includes physical capacity, i.e., having space to provide education and training to commence CSII, software and computers to provide follow-up care, and staff (expertise and resources) and time within the constraints of a heavy workload to provide the service. The most frequently discussed categories were related to resources (Table 3).

### Resources

All participants believed that the significant workload and understaffing of all groups of HCP is one of the most important barriers to access CSII. The presence of a MDT including dietitian and dedicated diabetes nurse specialist was a facilitator, and having more endocrinologists on the team was perceived to increase the chances that one of them will be interested in providing CSII. The “manpower” was seen as equally important, as individual attitudes and interest (see theme “[Impact of an] Individual”). Even if a consultant is trained and interested in CSII, but operates single-handed, access to CSII might be limited by the heavy workload. Furthermore, while leadership and a trained team are important to set up a CSII clinic, any loss in resources may temporarily curtail an established service and stop the CSII provision: *someone went off on sick leave or went off on maternity leave, the insulin pump list per se would be put on hold* (OKS 1, Appendix S4, Q22–Q24).

Associated with Resources, Expertise of the MDT members in CSII was perceived as essential to provide the training to commence it. Firstly, HCPs have to be trained in CSII (in particular nurses and dietitians), and the skills need to be regularly applied for their expertise not to be lost. Some HCP may not be exposed to CSII during training and the expertise of the endocrinologist is often obtained abroad, and reflects a personal interest in T1DM. Secondly, diabetes clinics usually cooperate with company reps who provide technical training for patients and these links should be established. Thirdly, a lack of continuity of care was described as a barrier by both HCP and PwD. Fourthly, confidence in CSII provision has to come from the exposure to PwD on CSII, as even the best CSII training will not be effective if a HCP is not exposed to pumps in clinical

practice. Finally, an important part of the capacity is support from hospital management. To sum up this theme: *the complexity of diabetes care has increased both in terms of the individual but equally in terms of the technology. All of these add extra burden to the clinic workload and that does not seem to be responded to by the health management* (OKS 3). Overall, it was reported that if there is no capacity, it is unlikely that CSII will be advertised or promoted, thus it may affect the awareness and exposure to pumps (Appendix S4, Q25–Q28).

### (Impact of an) individual

The most discussed theme impacting on CSII uptake was related to individuals: their interest, passion, leadership skills (HCP); empowerment and motivation (PwD); cooperation between HCP and PwD. Two separate categories related to HCP, and PwD are discussed in more detail, two others in Table 4.

#### Health care professionals (HCP)

HCP's attitude was the most significant and widely discussed barrier to or facilitator of access to CSII. According to participants, HCP (mainly endocrinologists) "are the gatekeepers". *If they don't see the need for pump therapy, then it is going to be very challenging for you to get your hands on a pump. So, they are a key barrier or facilitator. But my understanding is there is a wide variety of attitudes toward pump therapy. Some consultants are very supportive and others not so much. So, HCP and their attitude toward it as gatekeepers is absolutely huge* (PwD 6, high uptake). HCP who are interested in technology and "happy" to provide CSII were described as supportive, committed, and interested in CSII and T1DM, "willing to keep the doors open". As a specialist who provides diabetes care in Ireland is also trained in endocrinology, a lot depends on the personal interest of the HCP. *I am not really a diabetes guy, I am more of an endocrinology guy* (HCP3, high uptake). Specialists who are more interested in endocrinology than diabetes were seen as less likely to offer CSII. Both, PwD and HCP highlighted not only the interest, but also the leadership of a consultant, and a "can do attitude" as being a facilitator. *It is funny how one member of staff can make a difference* (OKS 1). Conversely, lack of interest in CSII and leadership skills were a HCP-related barrier to CSII provision: *If a consultant has no interest in insulin pump or never trained, or an endocrinologist who has no experience in that and has no interest in developing it, it will never develop* (HCP4, high uptake). Some of the reticence to commence CSII could be explained by "fear of the unknown", as well as endocrinologist's age (Appendix S4, Q29–Q32).

#### People with diabetes (PwD)

Key facilitative features of those accessing technology were: persistence, empowerment and motivation. Some HCP suggest that the patient should be the person asking about CSII. Many PwD argued that they need to "push", rather than "ask" to access CSII even in areas where uptake is high. *You ask for a pump, but if you are not coming and screaming, they just put you down on the list, and then... there is a "list". But where is that "list"? On the computer! So I think that if you are not really looking for it, and until you are not really engaged, they just keep you on "the list"* (PwD7, FG2, high uptake). There was agreement among all PwD in this study that they have to fight to access technology, in particular in rural areas. *I went into XXX and I was like: "it's as simple as this, I'm not leaving until you give me a letter to go to the YYY". I said "I'm done with injections" like* (PwD8, FG, low uptake). Other ways of "fighting" included: "being vocal"; contacting politicians; involving media and government to "push" hospital management. All participants agreed, however, that adult PwD were generally less effective in advocating for the use of CSII than parents of children with diabetes, who were more concerned with getting the best available treatment for their child. There was a consensus among all participants, that the main barrier to CSII from PwD side was lack of willingness to do so or a lack of interest in diabetes. Some PwD "don't want to be attached" to anything, or report that CSII does not suit their lifestyle and needs, and this preference should be respected. The lack of initiative and motivation to consider CSII might sometimes be determined by poor empowerment, diabetes stigma or even burnout—or that the current treatment just satisfies PwD's current needs and they have no preference to commence CSII. Reliable information about CSII should be provided to PwD in Ireland to enable them to make an informed decision regarding commencing CSII. Other aspects of this theme included individual cooperation, and the "conjunction" between HCP and PwD was seen as facilitator. If there is no cooperation, the only solution PwD saw was to "move consultants" and find an individual who is not a "gatekeeper" (Appendix S4, Q33–Q37). The differences between the HCPs and PwD are presented in Appendix S5.

### Discussion

This research reveals multiple factors that impact on the uptake and availability of CSII and gives a deeper understanding of the complexity in access and how it is affected by the health-service delivery. The "Conceptual Framework of accessing diabetes-related technology" (Fig. 1) presents the factors determining the access. Although reimbursement is offered in Ireland, uptake is low, and this is not

only limited by understaffing, or the clinics' capacity, or PwD preference, but by the lack of structure, awareness and individual preferences of PwD and HCP. The main finding of this study is that if the structure of the health-service is insufficient (e.g., lack of standardized criteria or a referral pathway) and the quality of care is not standardized, CSII not always included in specialist training), and if capacity is poor (e.g., under-resourced clinics, lack of expertise), CSII uptake appears to be impacted by individuals: their interest, leadership skills, willingness and motivation. These factors may make the regional differences in accessing diabetes-related technology and the quality of care more evident. According to all participants, adult PwD, HCPs and key stakeholders should continue the fight to improve the uptake and access to technology by being vocal, and by highlighting the gaps to policy-makers and politicians. There is a role to play by the national policy in Ireland that can give direction and establish a structure for health care providers, improve HCP' awareness and be a useful tool to improve CSII uptake. For example, the pediatric model of care for CSII in children under five [30, 31] was highlighted in the study as one of the determinants of the higher uptake in children. There was consensus that adult T1DM care can learn from pediatric care, as the type of diabetes is the same. Another facilitator of policy-making was felt to be networking and cooperation between all stakeholders, (HCP, PwD and politicians); there was a belief, however, that diabetes is not prioritized by politicians in Ireland in part, it was felt that it is a consequence of the character of diabetes—that is not “painful” or “visible” compared to other conditions, e.g., cancer. (Appendix S4, Q20–21).

Despite the issue related to resources (work overload, lack of a MDT), that has been considered as a barrier in CSII access by the audits in the UK [19], Italy [32, 33] and Ireland [16], the most important and frequently discussed theme was related to the impact of an individual. Willingness and demand of PwD is an important barrier or facilitator, and has been discussed in previous research. Tanenbaum et al. investigated barriers to device use reported by adults PwD in the T1D Exchange registry—the main barriers included associated costs and insurance (specific to the US), and physical barriers to wearing devices [18]. Study of parent-reported barriers highlighted the same—the physical burden, socio-economic factors (perceived financial barriers), and the therapeutic effectiveness of the device [17]. A review focusing on the adoption of CSII concluded that the barriers to acceptance for the person with diabetes “include the tension between the expectations of the device and the actual experience” and that for improved integration, early conversations are needed from HCP [34]. These studies, however, investigate the barriers when PwD are “offered” a pump by their diabetes teams, whereas we state that the main barriers or facilitators are

more complex, and are more focused on the fact that PwD “are not being offered” CSII, for complex reasons. The results of T1D Exchange study suggest 60% uptake of pumps in 38 adult clinics in the USA [15], which is 5 times higher than the 12.5% uptake in 21 Irish clinics that are offering training to commence CSII [16] in Ireland. Thus “interest of PwD” clearly is not the main barrier in Ireland.

The role of HCP's attitudes, interest and engagement is not usually highlighted as a barrier to CSII. The non-adoption, abandonment, scale-up, spread and sustainability (NASSS) framework—a massive analysis of technology implementation frameworks—claims that the “adopter system” is important, and that staff' non-engagement and non-adoption play an important role in the implementation process of any new treatment or technology use [27]. Our findings related to the impact of individual highlights the importance of the unification or standardization of HCP's approach to care provision. As reported elsewhere, consistent and relevant information is essential for provision of effective diabetes self-management [35]. The recently published “Pathway to Choice” (JDRF, 2020) highlights “the importance of HCPs in engaging people in technology use” as crucial for accessing T1DM technology choices [36].

There was an agreement among participants that the findings of this study would apply not only to CSII but also to other diabetes-related technology, including CGM/FGM. The dawn of hybrid closed-loop systems is observed [37, 38] and, as research aiming to cure T1DM is not yet successful, there is a belief that “technology is the cure” for T1DM [39]. If access to pumps is limited, access to other technological advance is likely to be limited also.

Limitations of the current study should be noted. Firstly, it was conducted in Ireland. Therefore, some of the barriers or facilitators might be specific to the Irish health-system. Secondly, the data were collected and analyzed by K.A.G., who is a diabetes educator (CSII trainer) and a PwD; thus, the possibility of a researcher-based bias should be acknowledged. Thirdly, the recruitment was based on social media, local support groups, and announcements in diabetes clinics—therefore it has to be acknowledged that all participants were already interested and engaged in their diabetes care, and that the opinions of those “non-attenders” or those not interested in diabetes care, or not actively engaging in DOC could be different. The snowball technique and purposive sampling used in the interviewees' recruitment may have been subject to bias, but the aim of this qualitative research was to get the purposeful, in-depth exploration of HCP views/experiences based on the richness of their experience and insights, not the “objective”, “common”, or “standardized” approaches used in quantitative studies. The results of this qualitative study are subjective views by participants and may not be generalizable to all PwD in Ireland or worldwide.



## Conclusion

To conclude, this study contributes to the scarce evidence on access to CSII (or any other complex diabetes technology) for adult PwD. Although technological advancements in diabetes are well-known and influence the quality of diabetes care and the lives of PwD, uptake is limited by lack of individual motivation and interest, health system structural issues, service capacity, awareness and PwD demand. The results of this study may inform HCP and policy-makers regarding gaps in the delivery of diabetes care, and suggest solutions to reduce the disparities in health service provision in the countries where reimbursement of diabetes technology is offered. Such steps may include the development of national guidelines, models of care, and structured approaches to provide equal access to CSII across the country.

**Acknowledgements** We would like to acknowledge Diabetes Ireland and Thriveabetes for their support in recruitment and data collection. We are grateful to all participants who took part in the study for their time, commitment and openness.

**Author contributions** All authors contributed to the study design and manuscript write-up. K.A.G. conducted the study and collected the data, transcribed and analyzed the datasets. R.B. and S.S. were involved in the final parts of the data analysis. All authors (K.B., R.B., S.S.) reviewed and edited the manuscript prepared by K.A.G. K.A.G. is the guarantor of this work and, as such, had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

**Funding** This research was funded by the Health Research Board (HRB) SPHeRE/2013/1 as a part of the PhD programme and K.A.G. is a HRB SPHeRE Programme scholar. K.B. is funded by a Health Research Board Award (RL-15-1579).

## Compliance with ethical standards

**Conflict of interest** The authors declare that they have no conflict of interest.

**Ethical approval** All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee of the Royal College of Surgeons in Ireland (RCSI) (Ethics reference no: REC Ref. 1494b) and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

**Informed consent** Informed consent was obtained from all participants at the time of data collection.

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